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ABSTRACT

The paper looks at the effect of a handicapped child on the family; the effectiveness of providing supportive assistance to such families; and strategies, techniques, or models for providing aid. The complexity of a parent's reactions to the birth of a handicapped child is pointed out, and family characteristics (such as poor health of the mother) which influence stress are considered. The framework of the family structure which includes a handicapped child is examined. Guidelines for Helpers (individuals who aid the family) in identifying family needs are offered. Noted among important qualities for Helpers are the ability to provide emotional support and ability to act in various roles including teacher and role model. Techniques and strategies for helping are seen to include developing an empathetic approach and addressing the family's informational needs using understandable terminology. (SW)

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HELPING THE HELPERS: INCREASING PARENT INVOLVEMENT

workshop presented for the
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Helpers, be they service providers or policymakers, all play important roles in improving the quality of life for children with handicaps. However, the people with the longest term, constant and most intense relationship with handicapped children are their parents. Professionals must be aware of how to help parents of handicapped children.

The importance of parental involvement in all aspects of the educational planning and placement process for handicapped children has been confirmed and reconfirmed. Yet excellent intervention programs may never realize their potential due to the collaspe of a concerned but overwhelmed family. While a child's handicap does not necessarily preclude the pleasures of parenthood, the satisfaction that may be realized by accomplishments of the child may be overlooked and overshadowed by the frustrations the parent experience. Professionals assuming helping roles must become aware of what it means to have a child who is handicapped in the family; the effectiveness of providing supportive assistance to families during such life crisis; and strategies, techniques or models for providing aid.

Parental Reactions to the Handicapping Condition

Traditionally, the birth of a new child into the family is an occasion marked by much happiness and dreams about the child's future. The birth of a handicapped child may not create a crisis for many families. For other families such a birth may mean that dreams about the future must be readjusted with the realization of the handicap. Being a parent is a complicated and demanding responsibility. When a child is handicapped, parents may sometimes find few of the typical joys that compensate for the

frustrations and inconveniences a child usually presents.

Few parents have been trained or prepared to deal with the situations and problems involved in parenting a handicapped child. A review of the literature on parents with a handicapped child reveals several common adjustment responses. Kubler-Ross (1969) researched the reaction of families to the loss or death of a family member, and observed five stages. These stages, commonly associated with the reactions experienced by parents to the birth of a handicapped child, include denial, anger, bargaining, depression, and acceptance. Similiar parental responses were reported by Livneh and Evans (1984) while observing the phases of adjustment to physical disability. These researchers described the following reactions: shock, anxiety, bargaining, denial, mourning, internalized anger, externalized aggression, acknowledgement, acceptance and adjustment.

In general, however, many parents in reacting to the facts regarding their child's handicap often refuse to believe there is a problem, feel angry and want to blame someone, feel guilty, look for the future, and finally adjust to the situation. For many families with a handicapped child, acceptance is never truly achieved. In fact, it is a deep, lasting change that life with a handicapped child brings. Consequently, the complexity of feelings about the child's handicap are often never fully resolved by parents. The negative feelings (i.e., shock, guilt and bitterness, etc.) stay on as part of the parent's emotional life. However, many parents do begin to adjust and/or accommodate to the facts, and begin realistically planning for the growth of the child.

Not every parent will go through all the stages described or go through the stages in the same manner or in the same sequence. However, it is

important to realize that a parent maybe in any one or none of these stages when they are requested by Helpers to become involved in the educational planning and placement process on behalf of their handicapped child. Furthermore, there are many incidents and crises during the development of any handicapped child that can reopen fears and feelings of denial, anger, depression or other signs of stress.

Family Characteristics Influencing Stress

Researchers have well established that the presence of a handicapped child in the family may be the source of much stress. However, in the application of research findings, Helpers are often not sensitive enough to the amount and extent of stress which the presence of a handicapped child may contribute to the dynamics of the family. Price-Bonham and Addison (1978) reviewed the literature on family stress related to having a handicapped child. These researchers reported increased divorce and suicide rates among parents of retarded children. Lonsdale (1978) conducted interviews with parents of handicapped children living in one city. Fifty-five percent of the parents felt that their relationship had been strained by having a child who was handicapped. Of the mothers, 33% had suffered with illness which resulted from having to look after a child who was handicapped. Fifty-one percent of the mothers felt they were prevented from working because they had a handicapped child. Moreover, 50% of the mothers felt that their social life was affected.

Gallagher, Cross and Scharfman (1980) explored the influence of the father in caring for the handicapped child. Measures of parental stress, social supports, parental-role function, and satisfaction were obtained

from 50 pairs of parents. Results indicated that 48% of fathers and 58% of mothers did not report measurable stress despite the presence of a handicapped child in the family. However, many families did experience mild to major stress (i.e., 58% of fathers and 48% of mothers). Several changes in behavior were noted by parents which resulted from having a handicapped child. Included in these parental behaviors were changes in sleeping habits, vacations, social activities, recreation, as well as sex difficulities.

Wikler (1983) examined periodic stresses in families with a handicapped child. Results indicated higher levels of stress were experienced by transition families (i.e., with an adolescent and/or adult handicapped child) as compared to non-transition families with a handicapped child in other age groups. Several types of stressor events were significantly higher for transition families. These events included excess time demands on the mother, limits on family opportunity, dependency needs of the child, lack of activities for the child, poor health of the mother, low family integration, and behavior problems of the child.

Holroyd and Guthrie (1979) compared parents of children with neuromuscular disease to parents of children with psychiatric diagnosis using the Questionnaire on Resources and Stress (QRS). Parents of children who were non-ambulatory scored significantly higher than those whose children were ambulatory on six QRS scales. These scales included excess time demands, over commitment/martyrdom, limits on family opportunity, physical incapacitation for the handicapped child, lack of activities for the child, and occupation limitations.

Roesel and Lawlis (1983) examined the relationship of divorce rate to

a diagnosis of genetic disability/mental retardation. The adaptive response of the families of such children would then be measured by their divorce rate. The sample consisted of families from a genetic screening and counseling services, and families from a state residential facility for the mentally retarded. Results indicated that when the divorce rate for the 2 groups were combined, there were no significant differences. However, results suggested that for young parents, the birth of a first born male handicapped child was significantly related to risk for divorce.

Family Systems Framework

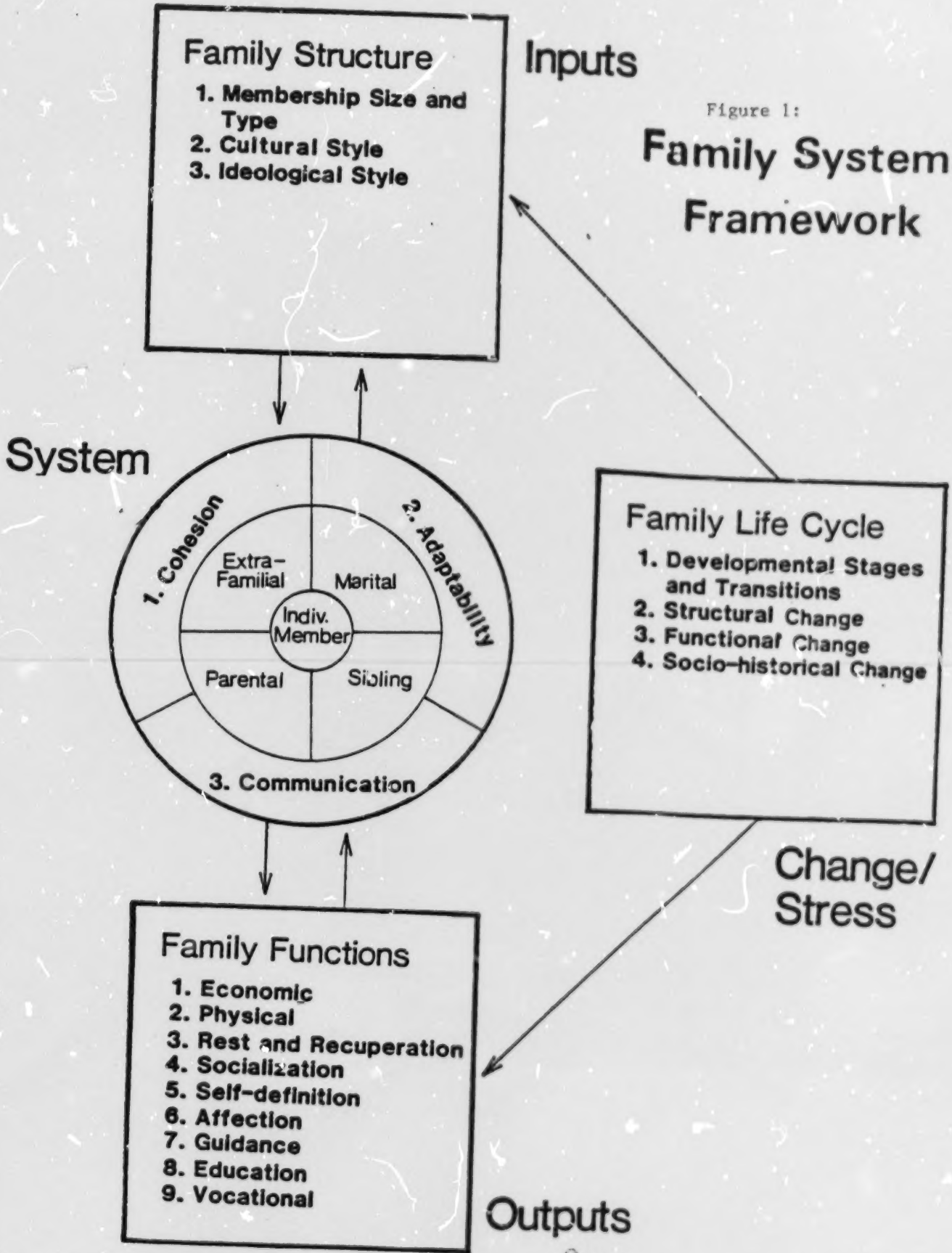
At birth, the handicapped child joins a family system. Figure 1 illustrates the pattern of relationships, structure, functions, and life cycle of the family system. All members within the system--including the handicapped child--interact with one another and are interrelated. However, the patterns of relationships and interactions among components must be examined by Helpers to better understand the needs of families.

With the realization of the handicap, in many instances, the child becomes the hub around which the family revolves. In such a capacity, the handicapped child becomes a significant contributor to family stress. Other characteristics which may influence the level of stress experienced by the family include factors associated with the parents, as well as the family structure.

The specific attributes of the child which contribute to stress include age--with increasing age increasing the difficulty in managing the child (Bristol, 1979); and the caregiving demands of the child (Beckman-Bell, 1980). However, many variables intervene to influence

Figure 1:

Family Systems Framework



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the impact of the parents on family stress. Income level, verbal skills, morale, personality characteristics, past experience, age and occupation each interact to mediate the parent's perception of stress in general. However, parents with more versatile defenses and more experience with stress sources are better able to handle stressful situations which may develop (Rabkin and Streuning, 1976). Another factor which may determine the amount and severity of family stress include the parent's view of the cause of the handicapping condition (Lavelle and Keogh, 1980). The nature and intensity of stress would then be related to whether the cause of the disability was perceived to be internal or external to the parent's ability to exercise control of the situation.

In terms of family structure, the income level and the size/type are important considerations in determining the intensity and degree of stress. Low income families with a handicapped child experience more stress than families who are financially more secure (Rabkin and Streuning, 1976). Importantly, low income families encounter more severe stress in meeting the basic demands of daily survival. Such stress is independent of the problems presented by the handicapped child. Further, it has been identified that income level influence the strategies that parents utilize in interacting with their handicapped child (Ramey, Mills, Campbell, and O'Brien, 1975). Lastly, Beckman-Bell (1980) concluded that one parent familes of handicapped children experience more stress than two parent families. Such stress is reflected in increased demands on the time and responsibilities assumed by the single parent.

When the birth of a handicapped child interacts with the family's resources for meeting a crisis, and with the family's definition of the event, a stressful situation may be produced. Helpers can be actively involved in offering supportive assistance during such a period. Helpers influence the family's definition of the crisis, as well as the family's resources for meeting the difficulties encountered. Helpers exert such influence by performing an information sharing, social support, and training function. The provision of information and support increases the family's stress adjustment resources. In addition, Helper to parent exchanges can redefine the definition of the stress, and thus lessen the severity of the definition of the event.

The birth of a handicapped child may affect a family's economic, physical and psychological functions. Financially, there is often great expenses involved in the care and education of a handicapped child. Adapted equipment, medical care--which may or may not be covered by health insurance, pleasurable toys which may be purchased to help compensate for a child's passive exploration of the environment, therapies, transportation to appropriate services, etc. may each be required for the optimal development of the handicapped child. Additionally, the physical and psychological strain on family members, related to the presence of a handicapped child in the family may also be tremendous.

Guidelines for Identifying Family Needs

The problems faced by both the family and the child are multifaceted and complex. One cannot deny that parents may have significant problems in dealing with the educational, psychological, financial and social

ramifications of their child's handicap. Therefore, Helpers need to be acutely aware of the needs of the family or have a mechanism established to identify needs. Professionals need information from parents about their children and their families, including developmental life changes. Such feedback from parents assist Helpers in analyzing individual family systems with respect to goals, values and priorities. In addition, such information assists in identifying appropriate family intervention goals.

It is important for Helpers to remember that parents are not homogeous groups. Factors such as sex, age, psychological support systems, religion, social class, etc. must each be considered in the needs assessment process. The need for networking, resource connecting, and the formulation of support groups are crucial to the progress of the child and the resultant family dynamics. Helpers must know the types of services that would be most appropriate for the family--especially those needed during life cycle transitions for the child and the family. Recognizing that the family which has the opportunity to find, support and develop a social network; to reduce stress; and to increase coping and management skills within their family system will be motivated and better equipped to participate and develop skills in education related issues.

In identifying needs of families with a handicapped child, Helpers must examine the family's environment and style. Factors to consider include where the parents are in terms of their adult life cycle development; the cultural and/or linguistic style of the family; the patterns of interaction in families, as well as between parent and child;

the quality of the husband/wife relationship; the role of extended family and friends; as well as the adaptability, communication, and cohesion of the family.

Examining the possible human and agency support services, the concerns identified by the family, and the type of help the family is requesting is also an important needs assessment activity for Helpers. Need areas may include financial, education, health, psychological and social support difficulties. Families with a handicapped child may be experiencing all, some or none of these needs. The severity of the need's appearance should determine the focus of intervention.

Helpers must provide parents with assistance in developing and/or enhancing support systems which will improve their ability to cope, enhance family relationships, and provide the means to obtain concrete skills in advocacy, resource information, and peer supports. After diagnosis of the handicapping condition, when feelings have been addressed, many parents make an emotional accommodation so that they can move forward as parents. However, parents may continue to struggle with distressing feelings for many years. These feelings may block appropriate parental behaviors. The actions of Helpers can give support, reality based information, and hope to parents.

Important Qualities for Helpers

As Helpers, professionals must have a working knowledge of techniques and strategies that will assist parents, with a handicapped child, cope and adapt to critical incidents involved in the care of the child. Consequently, certain essential characteristics must be exhibited by profesional working with parents of a handicapped child. These characteristics

include the ability to provide emotional support, provide clear and accurate information, enlist the help of other parents, and provide adequate training programs for parents (Karnes and Teska, 1980).

Table 1 summarizes some important qualities that characterize effective Helpers of parents with a handicapped child. Many of these qualities cannot be learned through in-service training. Collectively these qualities denote unconditional positive regard for all humans (i.e., because people exist they are worthy of living); that no human has a right to judge another; and that nothing can be substituted in any human interaction for openess, honesty and sincerity.

It is important to dissect and examine not only important qualities for Helpers, but also the roles assumed in a helping relationship. Included among these roles are that of teacher, sponsor, counselor, role model, reflective guide, confidant, and coach. In the role of teacher, Helpers provide relevant information to parents. While acting as a counselor, Helpers offer support and advice on an emotional level. As a role model, Helpers may offer self in interacting with the handicapped child and/or family members, allowing parents to choose aspects that meet personal needs. The role of reflective guide is assumed when Helpers provide parents of a handicapped child with information regarding the politics of the particular institution. Parents of a handicapped child are aided in developing self understanding as Helpers assume the role of trusted friend and confidant. Finally, Helpers ensure parent's ability to meet the demands of possible situations in their role as coach.

Table 1: IMPORTANT QUALITIES FOR HELPERS

The professional involved with parents of handicapped children should be:

understanding	tactful
honest	resilient
trusting	kind
compassionate	empathetic
caring	cheerful
helpful	dedicated
sensitive	enthusiastic
friendly	warm
supportive	courteous
loving	motivated
patient	persistent

Adapted from: Morrison, G. Parent Involvement in the Home, School and Community. Columbus, Ohio: Charles Merrill, 1978.

The listing of qualities and roles, required of professionals who work with parents of handicapped children, can serve as a self-checking guide. However, it is important to recognize that some professionals do not possess all of the qualities, and cannot assume all of the roles required in a helping relationship. It is important that Helpers recognize their own feelings and limitations, and know when it is appropriate to refer parents to other relevant professional.

Techniques and Strategies for Helping

Helpers must assess the parent's reaction to the child's handicap, and the level of need indicated through the family system. Helpers must get to know each parent as completely as possible in order to provide supportive assistance geared to the needs of each family. Most importantly, Helpers must develop an empathetic approach to working with parents of a handicapped child. Such an attitude would permit professional to assist parents in recognizing the birth of the child as an element in the continuum of adult life experiences (Prescott and Hulnick, 1979).

Helpers must clarify what is confidential, in the information shared through the helping relationship, in order to build trust. Additionally, Helpers must develop active listening skills; must gather information that will assist in understanding the functioning level of the family unit; and must address the informational needs of the family using understandable terminology.

These strategies and techniques would enable Helpers to provide supportive assistance to connect families with resources and materials that provide maximum benefits to the handicapped child and his/her family. Such intervention methods represent a preventive approach that would

help families with a handicapped child develop a proactive stance as opposed to merely reacting to stress.

Summary

Currently, there is a growing trend toward keeping a handicapped child within the family unit. This trend creates a need to help families with a handicapped child adapt to problems which may become manifest. Professionals must help parents see how interesting and unique their handicapped child may be. In order to encourage the family's role in the child's development, Helpers must communicate that they value family members as people and their development and accomplishments as goals worth striving for.

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